TESTIMONY OF MARK A. ROTHSTEIN
INSTITUTE FOR BIOETHICS, HEALTH POLICY, AND LAW
UNIVERSITY OF LOUISVILLE SCHOOL OF MEDICINE

before the

SUBCOMMITTEE ON THE FEDERAL WORKFORCE
AND AGENCY ORGANIZATION

HOUSE COMMITTEE ON GOVERNMENT REFORM

Using Information Technology: For the Health of It

St. Louis, Missouri
September 1, 2006

MR. CHAIRMAN and members of the Subcommittee. My name is Mark Rothstein. I am the Herbert F. Boehl Chair of Law and Medicine and Director of the Institute for Bioethics, Health Policy and Law at the University of Louisville School of Medicine. I am also Chair of the Subcommittee on Privacy and Confidentiality of the National Committee on Vital and Health Statistics, the statutory public advisory committee to the Secretary of Health and Human Services on health information policy. I am testifying today in my individual capacity.

I am pleased to testify about the significant privacy and confidentiality issues surrounding the conversion of our health records system from paper to electronic form and the linking of electronic health record systems through an interoperable network to create the Nationwide Health Information Network (NHIN).

Many individuals are concerned about the potential for sensitive information to be divulged through negligent or intentional acts of snoops, hackers, rogue employees, or – as we've seen recently in other contexts – the careless storage of sensitive information. Although these concerns are valid and demand strong security measures, I want to focus on more fundamental questions of privacy and confidentiality. In short, as we move from paper to electronic records, it's not just the form of the records that will change – it's the magnitude and nature of the contents.

Today, the number one protection for privacy and confidentiality of individual health information is the fragmentation of the health records system. It would be practically impossible to aggregate all of the paper health records for the typical adult who has lived in several places and who has seen numerous health care providers for a myriad of conditions over many years. In an electronic health records system, however, the

fragmentation will be gone. That's a good thing for a variety of individual and public health reasons. But, it will mean that with a few key strokes, health care providers will be able to obtain all of an individual's health records. In many cases, the old records will have no medical relevance or clinical utility to the reason the person is currently being treated. Furthermore, the old records may contain extremely sensitive information related to domestic violence reports, drug and alcohol treatment, reproductive health, sexually transmitted diseases, mental health, and other matters.

An even more troubling implication is the fact that individual health records are frequently used in non-health care settings. It is common for employers, life insurers, and other third parties to condition a job or an insurance policy on an individual signing an authorization for the release of his or her health records. Such practices are legal. According to my research, there are approximately 25 million compelled authorizations in the U.S. each year. Today, sensitive health information is disclosed to numerous entities, many of which are not covered under the HIPAA Privacy Rule. In the future, the volume and detail of these records will increase greatly.

In designing the NHIN, individuals need to be given a meaningful say in how their records are linked and disclosed. To date, however, there has been inadequate consideration of the specific rights of individuals to, for example, opt in or out of the NHIN or to control what records are disclosed and to whom. There also has been little effort in researching the feasibility of privacy-enhancing technologies that could be incorporated into the NHIN. If such measures are not included within the NHIN architecture, it may be too late or prohibitively expensive to add these features in the future.

Mr. Chairman, our health records system and our health care system in general are based on the trust that individuals have in their physicians, nurses, and other professionals to safeguard their confidential information. If we develop an interoperable, comprehensive health records system that undermines patient trust, then the political support for the NHIN will be destroyed and substantial numbers of individuals are likely to engage in defensive practices to protect their privacy that could jeopardize their own health and the health of the public.

I thank the members of the Subcommittee, and I look forward to your questions.